

# Making a decision about:

# **Dupuytren's contracture**

#### What is this document?

This document is called a decision aid. It is designed to help you decide between treatment options. You should go through it and talk to your healthcare professional.

It is for people who have been told they have Dupuytren's disease. Surgery will be an option when one or more of your fingers are bent and you cannot put your hand flat on a table top, *and* you feel Dupuytren's is starting to impact your daily life.

Pages 1 – 5 should help you make a decision

Pages 6 – 8 have extra information

## What is Dupuytren's?

Dupuytren's affects the tissue under the skin of your palm or fingers called the fascia. The fascia becomes thicker and less flexible. Over months or years, it can make your fingers bend towards your palm. This bending is called a contracture. Dupuytren's can sometimes be uncomfortable or painful. There is no cure yet for Dupuytren's disease. Treatment can help to straighten your fingers and may improve the use of your hand, but it does not get rid of the disease.

Needle fasciotomy and open surgery are usually an option if your finger is bent at an angle of over 30° like this

Proximal interphalangeal joint (second finger joint)

Metacarpo-phalangeal joint (first finger joint)

Progression of Dupuytren's disease

The first sign is often a small hard lump in the palm of your hand called a nodule.

Nodules may then thicken into a cord that restricts movement of the fingers.

## Your treatment options:

There are several options for treatment of Dupuytren's contracture. Which is best for you will depend on your contracture and personal feelings. **Some other options for early disease are described on page 6.** 









# **Do nothing**



This means having no treatment. It is always your choice whether to have treatment or not. If your Dupuytren's contracture isn't impacting your daily life you might not want to have treatment. Your contracture may not get any better, but it may not get any worse. You can always decide to have a procedure later but if your finger(s) become very bent, treatment may not work as well.

# **Needle fasciotomy**



Your hand will be numbed (using local anaesthetic) and a needle will be inserted in several places along your palm and finger. This will loosen and then snap the thick tissue which causes your Dupuytren's contracture.

It can only be carried out if your contracture is clearly visible (you can easily see the cord). A healthcare professional will be able to tell you if this applies to you.

# **Open surgery**



#### **Fasciectomy**

Your hand will be numbed (using local anaesthetic) or you may be put to sleep (using general anaesthetic). Cuts will be made along your palm and finger and the thick tissue causing the contracture will be removed. This is the most common surgery for Dupuytren's contracture.

### **Dermofasciectomy**

This is similar to a fasciectomy but you will also have a skin graft taken from elsewhere on the body. This is because some of the skin from your palm or finger is removed along with the contracture. This procedure is usually carried out in people under 40, people who have already had a fasciectomy in the past, or people whose skin is involved in their contracture.

When you have treatment for your Dupuytren's contracture it does not cure the disease.

That means there is a chance that your Dupuytren's contracture will return after treatment.

This is called recurrence. It can return to the same finger and hand or a different place.

The risk of recurrence depends on your age, the severity of your disease and the treatment carried out.

#### **Glossary of terms:**

Fascia are your connective tissuesOtomy means to cutEctomy means to remove

Your personal feelings are an important part of making a decision. Think about what matters most to you in this decision. On each question below, consider your answer and put a mark in the yes or no box, then talk the answers through with your healthcare professional.

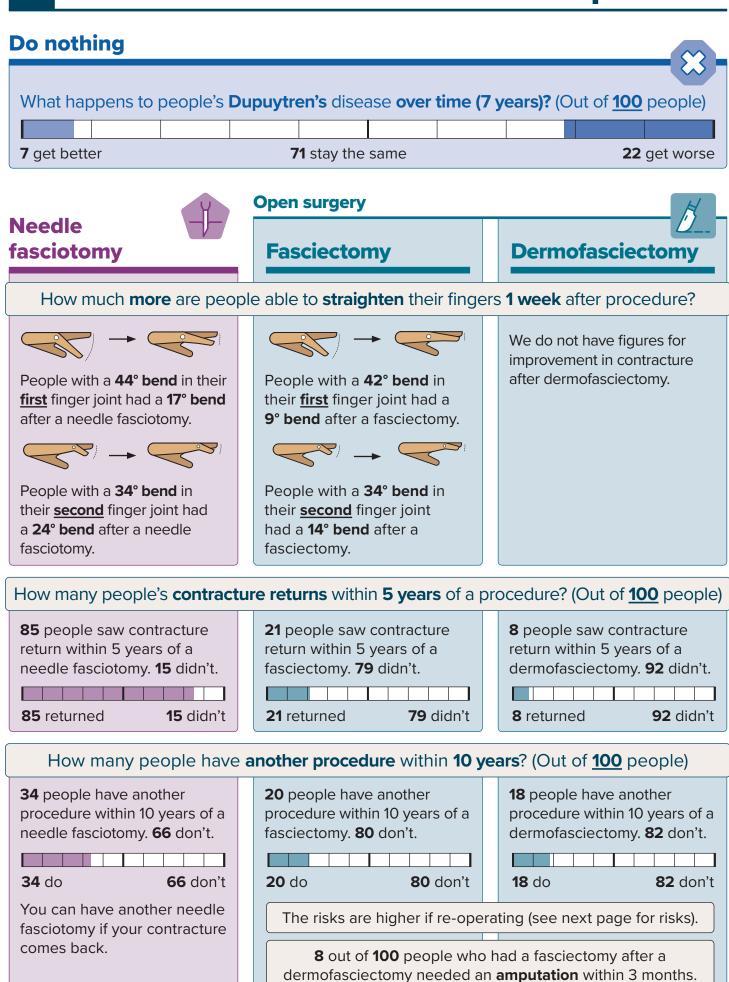
	Put an ' <b>X</b> ' where	it applies to you
	Yes	No
I struggle with daily activities (because of difficulty gripping and clumsiness)		
I think the benefits of surgery are worth having a procedure		
I would like a procedure even though my contracture could come back		
If you've mainly marked no: doing nothing may be a good option	1.	
<b>If you've mainly marked yes:</b> needle fasciotomy or open surgery be worth considering.	may	
If you've mainly marked yes: needle fasciotomy or open surgery		

If you have more 'yes' answers or still want to consider a procedure, complete the next three boxes.

<u>_</u>		
	Put an ' <b>X</b> ' where i	t applies to you
	Yes	No
A healthcare professional has told me I am suitable for needle fasciotomy		
I don't mind a higher chance of my contracture coming back		
I would prefer a procedure with a shorter recovery time		
If you've mainly marked no: open surgery may be a good option		
If you've mainly marked yes: needle fasciotomy may be a good of (if you are suitable).	option	

# 4

# Potential benefits and risks of options



# 5

# **Potential risks of the treatments**

	Open surgery	
Needle fasciotomy	Fasciectomy	Dermofasciectomy
	ny people have <b>long-term nerv</b> enumbness) in their fingers? (Ou	
2 people have long-term nerve damage after a needle fasciotomy. 98 don't.  2 do 98 don't	3 people have long-term nerve damage after a fasciectomy. 97 don't.  3 do 97 don't	6 people have long-term nerve damage after a dermofasciectomy. 94 don't.  6 do 94 don't
	ople have <b>'complex regional p</b> and pain in the fingers)? (Out c	•
1 person has complex regional pain syndrome after a needle fasciotomy. 99 don't.  1 does 99 don't	<ul> <li>4 – 10 people have complex regional pain syndrome after a fasciectomy. 90 – 96 don't.</li> <li>4 – 10 people have complex regional pain syndrome after dermofasciectomy. 90 – 96 don't</li> <li>4 – 10 do 90 – 96 don't</li> <li>4 – 10 do 90 – 96 don't</li> </ul>	
	ople have <b>short-term skin dam</b> n after surgery? (Out of every <u>1</u>	_
20 people have short-term skin damage after a needle fasciotomy. 80 don't.  20 do 80 don't	<ul> <li>5 people have wounds that reopen after a fasciectomy.</li> <li>95 don't.</li> <li>5 do</li> <li>95 don't</li> </ul>	10 people have wounds that reopen after a dermofasciectomy. 90 don't.  10 do 90 don't
How long does	it take people to <b>recover</b> from	the procedure?
It takes less than <b>2 weeks</b> to recover from a needle	It takes <b>4 – 12 weeks</b> to recover from a fasciectomy.	It takes <b>6 – 12 weeks</b> to recover from a

**Open surgery on the hand is a major operation**. Your wounds should heal within a few weeks of surgery, but full recovery time may take many months. You will need physiotherapy during this recovery period.

dermofasciectomy.

These procedures do have other risks but we don't have numbers for them, for example:

• risk of infection after the procedure

fasciotomy.

- risk of long-term joint stiffness after open surgery
- risk that the skin graft in dermofasciectomy won't work.

# 6 Other treatment options

The options on this page are for early stage Dupuytren's disease (before you have a contracture of 30°).

# Other treatment options for early stage Dupuytren's disease

### Radiotherapy

There is some evidence that radiotherapy may slow the progression of the Dupuytren's contracture in its early stages. It is rarely offered on the NHS but it is available privately, which means you would have to pay for this treatment. **One study that looked at what happened to 135 people 13 years after radiotherapy:** 

**10** out of **100** people's bending **got better** –

59 out of 100 people's bending didn't change

31 out of 100 people's bending got worse -





5 – 64 36 – 95



Between **20** and **43** people out of **100** had **short-term red, sore or dry skin** after radiotherapy. **57** – **80** didn't.

Between **5** and **64** people out of **100** had **long-term dry skin** after radiotherapy. **36** – **95** didn't.

Between **5** and **13** people out of **100** had **long-term skin** wastage (called atrophy) after radiotherapy. **87** – **95** didn't.

There is a **very small risk** of **developing cancer** with radiotherapy, the chance of this happening is thought to be around **1 in 5,000**.

# Pain relief

Some people develop painful or uncomfortable nodules on their palm or finger. There are some options that can help manage or reduce this pain.

#### Corticosteroids

Sometimes steroid injections can be used to treat the early stages of Dupuytren's contracture. These injections do not help with the bending of your fingers but they may help ease painful nodules on your palm or fingers.

In **97** out of **100** people, **nodules soften and flatten** after 3 injections.



In **50** out of **100** people, **nodules returned** within 1 - 3 years.



## **Physiotherapy**

There is little evidence that physiotherapy will help slow the progression of Dupuytren's contracture. But if you are feeling pain and tension in your hand, exercises may provide some relief.

## What causes Dupuytren's disease?

The exact cause is unknown. You are more likely to get the disease if:

- · you have close relatives with Dupuytren's
- · you smoke or you drink a lot of alcohol

· you have diabetes or epilepsy

· you are a man.

If you are diagnosed with Dupuytren's disease you may also get disorders affecting tissue elsewhere in the body. These can affect the feet (called Ledderhose disease) or the penis (called Peyroine's disease).

# How many people have Dupuytren's disease?

Dupuytren's disease can develop at any age but you are more likely to get it as you get older.

Aged 55



**12** in every **100** people aged **55** have Dupuytren's

Aged 65



21 in every 100 people aged 65 have Dupuytren's

**Age 75** 



**29** in every **100** people aged **75** have Dupuytren's

## Where can I go for more information?

NHS: https://www.nhs.uk/conditions/dupuytrens-contracture/

FAQs: https://dupuytrens.org/faq/

Patient Info: https://patient.info/bones-joints-muscles/dupuytrens-contracture-leaflet

British Dupuytren's Society: https://dupuytrens-society.org.uk

#### Where did we get our numbers from?

#### Page 4:

- What happens over 7 years from study of 93 people https://doi.org/10.1302/0301-620X.103B4.BJJ-2020-1364.R1
- Improvement in angles after surgery from a study of 113 people https://doi.org/10.1016/j.jhsa.2006.02.021
- Recurrence rates after 5 years for needle fasciotomy and fasciectomy from a study of 93 people https://doi.org/10.1097/PRS.0b013e31823aea95
- Recurrence rates after 5 years for dermofasciectomy from a study of 103 people https://doi.org/10.1302/0301-620X.82B1.0820090
- Reoperation rates after 10 years from a study of 121,488 people https://doi.org/10.1038/s41598-020-73595-y

#### Page 5:

 Potential risks from a review of 113 studies (20,020 people) https://doi.org/10.1016/j.hansur.2017.07.002

#### Page 6

- Benefits of radiotherapy from a study of 135 people https://doi.org/10.1007/s00066-010-2063-z
- Potential risks of radiotherapy from a review of 6 studies (698 people) https://doi.org/10.1177/1753193417695996
- Benefits of steroids from a study of 63 people https://doi.org/10.1053/jhsu.2000.18493

#### Page 7:

• Prevalence of Dupuytren's disease from a review of 10 studies https://doi.org/10.1097/01.prs.0000438455.37604

# 8 Next steps

Once you have worked through this information you can use this space to write any questions you would like to discuss with your healthcare professional. Bring this document to your next appointment.

nta	ctc
пта	CLS

Name of doctor, nurse or specialist	What are their contact details
Contact details of hospital transport (if applicable)	

# **Next steps**

What will happen to me next? (treatments / tests?	')
When will these happen?	When will I be reviewed next?
What decision do I need to make today? Or when	n do I need to make a decision?

# **Questions for your specialist**

These can be about any concerns you may have, for example what you hope for from your treatment decision